

Giving Young Carers a Voice Quarterly Insight Report

What we're hearing

April to June 2025



Giving Young Carers a Voice

Quarterly Insight Report – April to June 2025

What we’re hearing

If you would like a paper copy of this document or require it in an alternative format, please get in touch with us.

Contents

About Luminus.....	3
About Giving Carers a Voice	3
Engagement April to June 2025	3
Main themes we have heard from April to June 2025	4
Where we have shared our insight.....	4
Where we have heard from young carers.....	5
Key themes we have heard from young carers from April to June 2025	5
Caring for someone with complex health needs	5
Understanding what a young carer is and how attitudes can affect them	7
Caring for a sibling with ADHD and autism.....	9
Carers Week school sessions	10
Impact.....	10
Signposting	11
Thank you	11
Contact us.....	12

About Luminus

Luminus is a Surrey based independent community interest company which exists to empower people to have their voices heard. We are an enterprise driven by social value, that invests in the local community. We help organisations provide equity of access, and the best services possible, through the inclusive involvement of local people. Our vision is to create a society where everyone's voice is heard so we all receive the support we need for our wellbeing.

Our CIC was originally established in 2013 to deliver the [Healthwatch Surrey](#) service and ensure the voices of all users of NHS and social care services are heard. We have since built on our expertise and experience and Luminus has grown to shine a light on the experiences of carers, young carers, those who are affected by substance use, and people most at risk of health and care inequalities. We achieve this through bespoke projects, co-design, contracts, mentoring, research, and training.

About Giving Carers a Voice

Giving Carers a Voice listen to the experiences of carers (of all ages) to ensure their views are heard in the design and delivery of the services they use.

If people look after anyone who couldn't manage without their help, they are a carer.

Engagement April to June 2025

This quarter, we have visited the following places:

- Boxgrove School young carer group, Guildford
- Park Mead School young carer group, Cranleigh
- Sunflower Café, Godalming
- Ash Grange School young carer group, Ash
- Carers event, East Horsley
- North West Surrey Additional Needs Showcase
- St Peters Primary School young carer group, Leatherhead
- East Surrey College information sharing joint engagement with Healthwatch Surrey
- Hermitage School young carer group, Woking
- Additional Needs Showcase, Ripley
- Pro-Active, Managing my Health event, Woodhatch
- Godalming College, Godalming
- Royal Surrey County Hospital open day, Guildford.

This quarter, we have attended the following meetings:

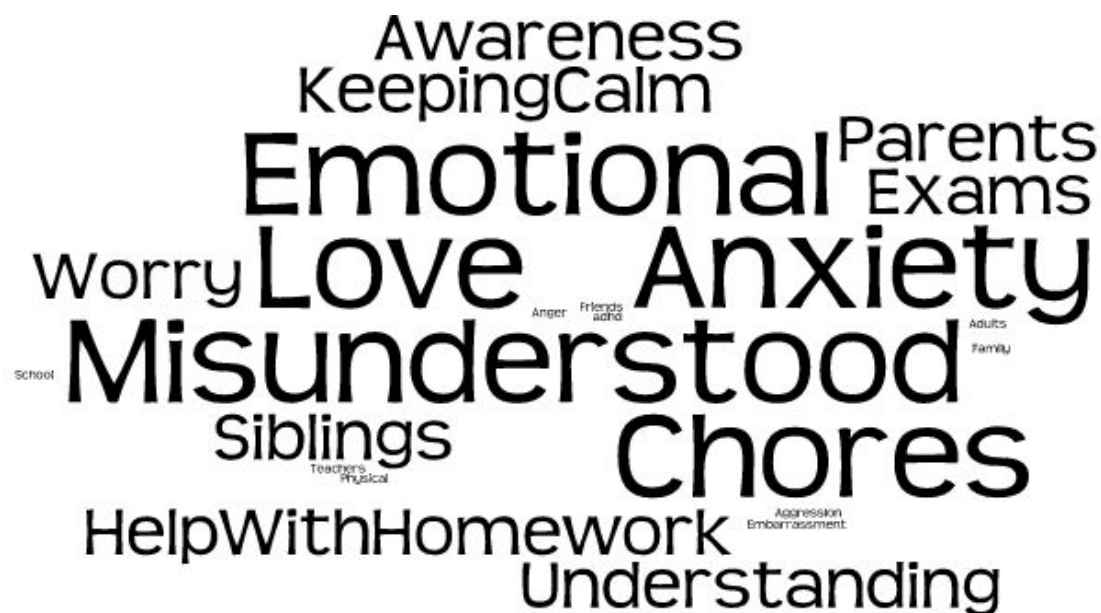
- North Tandridge health and wellbeing network
- National Autistic Society parent carer group



- Young Carers Alliance, Supporting Younger Young Carers
- Surrey and Borders Partnership, Carers Action Group
- East Surrey health and wellbeing network, East Surrey College
- Surrey Healthy School Approach training
- Surrey Youth Focus, Early Years Community of Practice, Children's Neurodiversity event
- South Tandridge health and wellbeing network meeting
- Carers Trust, young carers supporting someone with a mental illness.

Main themes we have heard from April to June 2025

The word cloud below highlights the main themes we have heard about this quarter. The most prominent words are Misunderstood, Anxiety, Chores, Emotional, and Love.



Where we have shared our insight

During this quarter we have shared young carer insight (key themes and young carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings:

- South Tandridge health and wellbeing neighbourhood meeting – April 2025
- Mental health forum – April 2025
- Additional Needs Showcase, North West – April 2025
- Carers action group – May 2025
- North Tandridge health and wellbeing meeting, May 2025
- Epsom/St Helier Carers steering group – June 2025
- Surrey Youth Focus, Children's Neurodiversity event – June 2025
- Charity leaders forum – June 2025
- Additional Needs showcase, Ripley – June 2025
- Pro-Active, Managing my Health event, Woodhatch – June 2025.

If we hear a case of concern regarding a person's safety, we immediately signpost the sharer to the appropriate body and escalate the case with the provider/commissioner.

Where we have heard from young carers

This quarter, we have engaged with 114 young carers. The map of Surrey below shows the number of young carers we have engaged with in each area of Surrey.



Key themes we have heard from young carers from April to June 2025

- Caring for somebody with complex health needs
- Understanding of what a young carer is and how attitudes can affect them
- Caring for a sibling with ADHD and autism.

Caring for someone with complex health needs

Young carers exhibit remarkable strength, frequently managing difficult situations and acquiring an understanding of health conditions with impressive maturity beyond their years.

"My little sister has a genetic disorder (Coffin-Siris Syndrome). She goes to a special school because she needs more help than other children. She has learning difficulties and struggles to swallow, and she chokes on her food. She also has loose joints. I help her with lots of things, like dressing, washing, walking, reading and getting ready for bed. She sometimes wakes up really early and comes into

my room which I don't like very much. I don't mind helping her, she's my sister and I love her very much. Mum and dad have to do a lot more for her than I do. There isn't a young carers group at my school, and I don't know of any other young carers there. I like coming here, everyone is nice, and I've made some friends. We get to eat here, and we get snacks too. We also play lots of games and do crafts."

Carer, 9, April 2025

"My older brother is [age], and I've always needed to help him with things because he has Down's Syndrome. I enjoy helping him. We do our homework together because, although he's older than me, we are on the same level. He goes to a special school, and I would like him to be here with me at this school so that I can look after him. We do lots of things together, and he's very funny and plays lots of jokes on me. We like playing football and can be competitive, mainly because we support different teams. I hope when I go to senior school they have a young carers group. This group has helped me a lot and we have become friends."

Carer, 10, April 2025

"My younger brother is [age], and I became a young carer when he was born. He has agenesis of corpus callosum, which means that a part of his brain is missing. He struggles to walk, talk and do things which I can do. I can get impatient with him sometimes, but I don't mean to be unkind. I sometimes get frustrated when I can't get any time to myself. My mum is very good, and she'll talk to me and make sure that I'm ok. Because it's obvious my little brother is different, most people understand that I'm a young carer, they know that I help him and my mum to do things."

Carer, 12, May 2025

"I help to look after my dad. He finds it hard to walk and cannot get around very well, even in the house. I help him with walking, getting things for him and reading. He sometimes needs me to keep him calm. I usually give him big hugs and tell him I love him. We have a young carer group in school where I've made some friends, we do fun things, and we get snacks. I want to do more things outside school and go to the park more, or a big field where I can run around a lot. I have brothers who help too, and they look after me, they give me hugs and sometimes chocolate. I talk to them when I'm upset, and they speak to me too about Dad."

Carer, 9, June 2025

"I help my mum and dad do stuff they can't do. My mum has to take lots of pills every day because she's sick. My dad has a painful arm, so he can't do very much. I feed our cats and play with them too. I like to stargaze, and I'd like to do this more. I like school and the young carers group; we all care for someone."

Carer, 8, June 2025

"My brother has Hypotonia Ataxia, and Delayed Development Syndrome and walks with a frame. I help him with the toilet, walking and anything he cannot do himself."

Carer, 9, June 2025

"I'm a carer for my little brother. I have to make sure that he's happy and that he gets the right food. He has allergies, so I check the labels and ingredients for him. I have to tell people not to give him food without checking first. I like helping mum to do the cooking and doing things to help around the house. The young carers group in school is fun and I get to meet other people like me."

Carer, 10, June 2025

"I care for my sister who has Down's Syndrome. She takes longer to do things and doesn't learn things easily. I help her get dressed and undressed. I help her with her food, going to the toilet and getting into the car. I also help her at night if she wakes up."

Carer, 10, June 2025

"I help my mum to look after my grandma and grandpa. Grandma is having a difficult time with my Grandpa because he keeps shouting at her. He has dementia and gets very angry. I help with cleaning and finding things that grandma or grandpa have lost. I help around the house and with some cooking too."

Carer, 10, June 2025

Understanding what a young carer is and how attitudes can affect them

Negative and disrespectful behaviour not only affects the person with a disability, but also those who care and support them. Stigma or a lack of understanding about their situation can lead to shame and isolation. This can exacerbate any stress or anxiety they may already be dealing with. By fostering a more inclusive understanding through raising awareness and training in our community, we can create a more supportive environment for them, giving them a sense of value and inclusion. Understanding and supporting young carers is crucial in helping them manage being a young carer whilst also enjoying their childhood and reaching their potential.

"My sister has ADHD. I have to stay out of her way when she has a meltdown. She frightens me when she's angry and hits me. I get upset when she does this when we're out. People laugh and it's not funny. She's much bigger than me and when she hits me it really hurts. I don't think mum understands, all she's worried about is that my sister is looked after."

Carer, 7, April 2025



"My sister has ADHD. I help mum get her ready for school in the mornings. I make breakfast for us both and we walk to school together. I get embarrassed when she starts shouting for no reason. People stare at us. I get angry sometimes because my friends don't have to help their sister like I do, and they go out without including me. It's hard that I don't get to spend time with my friends, and they don't understand why I can't always go out with them, and I have to help my mum with my sister. I get upset when they start talking about all the things they have done in front of me."

Carer, 10, April 2025

"My [teenage] daughter has Turner syndrome and ADHD. She can become violent and aggressive. I'm aware this affects my younger daughter. I wouldn't have said she was a young carer because she doesn't provide any level of care for her sister. Thank you for explaining to me, and I will speak to her about registering at school and with Surrey Young Carers. It would help her to attend a group where she was able to talk through her anxieties, especially when her sister is being violent. She cannot have friends over because they are fearful of my other daughter and it caused a lot of problems with other parents when she was aggressive towards them. We just avoid any group activities. It's unfair on her younger sister, this is how it is and she has to deal with it. They don't have a young carer group in her school that I'm aware of, but I'll check. I don't know what would help her, but I'll certainly look at your suggestions."

Parent Carer, April 2025

"My brother is autistic. People with autism can't do things like talking or playing properly, but I love my brother with autism. Others don't understand when he's having a meltdown which upsets me."

Carer, 9, June 2025

"I look after my mum who can't walk very well. People stare at us when I'm helping her to stay steady. I help her with the cooking and chores around the house. I enjoy looking after people."

Carer, 10, June 2025

"My brother has ADHD and is very naughty. Mum can't take him shopping anymore, and when we go out, I get upset that people are looking at us and saying things which aren't very nice. Some people are really mean. Mum says it's because they don't understand and they think she's a bad mum."

Carer, 7, June 2025

Caring for a sibling with ADHD and autism

We continue to hear from young carers who care for a sibling with ADHD and autism.

"I care for my brother who has ADHD and autism. He gets very angry, and we fight a lot."

Carer, 7, April 2025

"I help to look after my little brother, who has ADHD. He needs help getting washed and dressed, as well as brushing his teeth. I read to him and play with him when mum is busy. I keep him calm too."

Carer, 7, April 2025

"I help to look after my little brother, who has ADHD. He needs help getting washed and dressed, as well as brushing his teeth. I read to him and play with him when mum is busy. I keep him calm too."

Carer, 8, April 2025

"My brother has ADHD. He hurts me a lot. We share a room and I can't always get away from him. I have to go to our bedroom whilst mum calms him down. I spend a lot of time away from him. I go outside and play football or go to a friend's house."

Carer, 9, April 2025

"My brother is autistic and mum has to spend a lot of time with him. We have to do things around him or he gets angry and mum finds it difficult to calm him down. This morning at home, my brother had a meltdown and I've been upset all day." (The teaching staff are aware, have reassured her and have been keeping an eye on her.)

Carer, 7, April 2025

"My older brother is autistic and has ADHD. He goes to a special school. I help him with things that he struggles with. He gets confused when getting dressed, so I'll help him. I make breakfast for him and we eat it together so that mum knows he's eaten."

Carer, 7, April 2025

"I care for my brother who has ADHD. It's hard to understand him, and when he's being difficult, I go to my room and read. When he's gone to bed, I can watch what I want on TV. My brother upsets me a lot, and I talk to my teacher, who understands what people with ADHD can be like. It would be helpful to have more support in school, particularly in areas such as homework, exam preparation, and managing anxiety. Exams are always stressful because I can't always revise in peace and quiet. It would help if there were a quiet area at school we could go to and

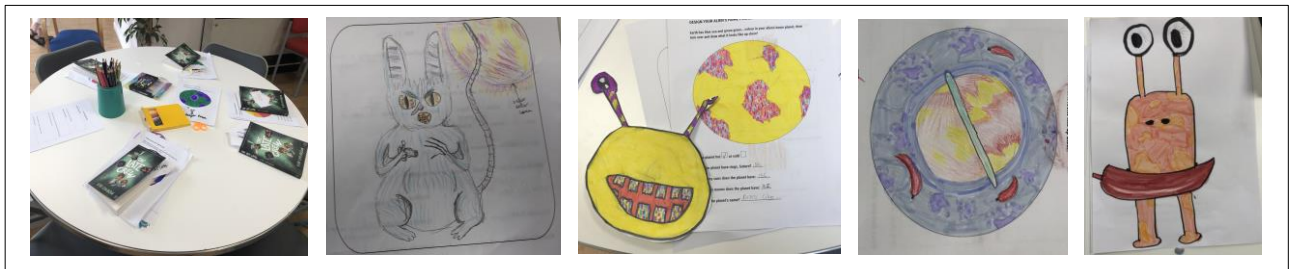
revise or do homework. Not all teachers understand what a young carer is, and I worry when I'm tired and my homework is not very good."

Carer, 12, May 2025

Carers Week school sessions

During Carers Week, Giving Young Carers a Voice had the pleasure of visiting two young carer groups in schools with Rab Ferguson, the Author of The Late Crew books ([The Late Crew](#)). In the style of the books, the young carers drew pictures of their aliens and the planets they lived on, describing their aliens' special powers and the appearance of the planets they inhabited. Rab read from his book and interacted with the young carers, drawing out their stories to be told. The young carers at both schools were thrilled to meet a real-life author and learn from him. It's wonderful to know that young carers can identify themselves with the characters in Rab's book and be encouraged to use creative writing to express themselves, whilst also being encouraged to read. Both schools purchased a copy of The Late Crew for each young carer, which Rab signed. Rab encouraged the young carers to write a 100 word story to be submitted and which could be published on The Late Crew website [Submit your Story! | The Late Crew](#).

Here are a few pictures from the day.



Impact

Engaging creatively with young carers provides both enjoyment and developmental benefits. Recently, the session with Rab in two schools demonstrated this potential, allowing young carers to express their experiences through imaginative stories about aliens. Participants were given the chance to share their personal stories if they wished. Many found personal connections to The Late Crew book, which is about a young carer supporting an autistic brother and a mother with chronic fatigue, which sparked insightful discussions as two friends related directly to the characters' struggles - one as a carer for an autistic sibling and the other for a parent dealing with chronic fatigue. One particularly vocal young carer, known for avoiding writing and disrupting class, experienced a significant transformation during the workshop. With Rab's guidance, he shared a compelling story and engaged fully, showcasing his untapped potential.

The book, The Late Crew, especially when brought to life by its author, thoroughly captivated all the young carers present. Rab's encouragement to submit a 100-word story was met with



enthusiasm, highlighting the workshops' effectiveness. This positive response motivates us to continue finding ways of creatively engaging with and uplifting the voices of young carers, fostering their growth and expression. One parent shared, "My daughter, who never reads books, finished the book in one evening and is now eager for me to buy the next one." And another "my daughter has just finished The Late Crew and enjoyed telling me all about it. She is now keen for me to buy the second book."

Signposting

On engagement, our team always signpost to appropriate support and care services. Sometimes, people do not want information given to them. Support services are provided where relevant. We also support individuals who require assistance with other issues, such as locating a support group in their local area.

We check in with the group leader if someone has said something we are unsure of or concerned about to ensure that the person is being supported and not alone. We also ensure that support services are aware of appropriate treatment pathways and local support available.

Thank you

A big thank you to everyone we have met and who has taken the time to share their experiences of being a carer with us. If you have a group you would like us to come along to and visit then please email us at info@luminus-cic.uk. We are very keen to hear from as many carers as possible from all over Surrey so we'd love to hear from you!

Our Giving Carers a Voice reports can also be found on our website page [Giving Carers a Voice: Reports - LUMINUS](#)



Contact us

Contact us through any of the channels below.

We'd love to hear from you:

-  Web: luminus-cic.uk
-  Telephone: 01483 301448
-  Text: 07592 787 533 (SMS only)
-  Email: info@luminus-cic.uk

Our address is:

Luminus, GF21 Astolat, Coniers Way, Burpham, Guildford, Surrey, GU4 7HL

